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# Using videoconsultations to deliver dietary advice to children with chronic kidney disease; a qualitative study of parent and child perspectives.

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## Abstract

**Objective:** Children with chronic kidney disease require specialist renal paediatric dietetic care, regardless of disease severity or geographical location, however under-resourcing makes this challenging. Videoconsultation may offer a solution but research exploring its acceptability is limited. The current study explored parent/carer and child perspectives of videoconsultation as an alternative or supplement to existing regional dietetic care.

**Method:** Children and families using a regional paediatric nephrology service were recruited through purposeful sampling techniques. Renal paediatric dietitians used existing hospital software to host videoconsultations with families. Perspectives were subsequently explored in telephone interviews with the children, their parents and separately with the renal dietitians. Data were transcribed verbatim and an inductive framework analysis conducted.

**Results:** Twelve families took part in the study comprising 13 parents and 5 children (9 months to 14 years). Two renal dietitians were also interviewed. Six themes emerged which were 'Logistics', 'Understanding Information', 'Family Engagement', 'Establishing Trust', 'Willingness to Change' and 'Preferences'. Satisfaction with the videoconsultations was high, with no data security fears and only minor privacy concerns. Parents reported that screen-sharing software enhanced their understanding, generated greater discussion and engagement compared to clinic and telephone contacts. Parents praised efficiencies and improved access to specialist advice, requesting that videoconsultations supplement care. Children preferred videoconsultations outright.

32 **Conclusion:** Dietetic videoconsultations were acceptable to families and perceived  
33 to be a feasible, high quality complement to regional specialist dietetic care.  
34 Enhanced understanding and engagement might improve self-care in adolescents.  
35 The acceptability and feasibility of videoconsultations could address inequitable  
36 regional service provision.

## Introduction

Videoconsultation (VC) is an internationally expanding branch of telemedicine that uses technology for real-time visual and audio patient assessment, monitoring and care-planning at a distance<sup>(1)</sup>. The United Kingdom (UK) Department of Health<sup>(2)</sup> recommends its use with patients, driven by increasing populations, perceived efficiencies and improved technology<sup>(3, 4)</sup>. Use of VC is recommended in the NHS Sustainability and Transformation Plan<sup>(5)</sup>.

In the UK, paediatric health networks provide co-ordinated, high quality pathways of care between general hospitals and specialist children's hospitals, enabling expert care close to home<sup>(6-8)</sup>. A specialist paediatric renal dietetic service is a requirement of a UK paediatric nephrology network<sup>(6)</sup> to support biochemical and symptom management and optimise growth and development<sup>(9)</sup>. Specialist dietetic support in early and late chronic kidney disease (CKD) reduces morbidity and mortality risk in infants and children<sup>(10)</sup>.

A UK report states that all children with moderate to severe CKD (stages 3-5D) should have at least one specialist dietetic appointment annually<sup>(6)</sup>. Equitable access is challenging, despite shared-care services<sup>(11)</sup>. Often only email or telephone support is provided to families who do not attend the specialist centre and there is concern that the lack of face-to-face consultations may lead to poor rapport and reduce opportunities to elicit useful health-related information<sup>(12)</sup>.

Anecdotally, the use of dietetic VC appears to be growing, although practise figures are unpublished. Ninety percent of UK children over eight years old regularly access the internet at home<sup>(13)</sup>. No studies exclusively report VC in a paediatric dietetic context and research is needed to investigate acceptability to patients, family members and dietetic professionals. Limited evidence of use in diet therapies is largely quantitative and relates to adults receiving advice from non-dietetic healthcare practitioners. This is compiled in a systematic review<sup>(14)</sup>, which concluded that all forms of telehealth, including VC, contribute to improvements in diet quality but child and family experiences and perceptions of dietetic VC remain unknown. The aim of this study was to investigate if virtual dietetic consultations are acceptable to parents, children and dietetic professionals.

## **Methods and Analysis**

### **Sampling and recruitment**

The study was conducted at Bristol Royal Hospital for Children (BRHC), UK and received ethical approval from the Health Research Authority (17/SC/0480).

A purposive, maximum-variation sample<sup>(15)</sup> was selected from the South West Paediatric Nephrology Network. This network included ten general hospitals who operate shared care with BRHC, to ensure a broad mix of child ages and CKD severity was captured across urban and rural locations. Participants were approached from January to May 2018 by renal dietitians, consultants or specialist nurses. All families had received previous dietetic support via email, telephone or in-person, to enable participant comparison of VC to usual care.

### **Equipment and data collection**

Existing hospital videoconferencing software (WebEx version 2.82, Cisco), with screensharing facilities and high security was used to connect a renal dietitian with families, using personal technology at home. Each VC took 15-30 minutes, and alongside webcam images, involved the renal dietitian displaying and discussing growth charts, blood results, diet sheets or feeding regimens via screen-sharing. Following this, within three working days, parents and children participated in a semi-structured, recorded telephone interview with a researcher using their speakerphone facility at home. During this telephone interview, parents and children were asked to describe their experiences and thoughts on the VC. An interview guide was developed using patient participant information (PPI) and used to maintain focus on the research objectives; this included prompts to gain perceptions of understanding, engagement, technological performance, rapport, concerns and future communication preferences. After the initial two interviews the guide was amended to further explore security and privacy concerns.

The two renal dietitians who carried out the VCs were interviewed by the researcher within 3 days of each VC, to enable validation of participant reports of technological performance, engagement and understanding, thus enhancing trustworthiness via triangulation of data<sup>(16, 17)</sup>.

100

## 101 **Data analysis**

102 All interviews were transcribed verbatim. Transcripts were read and re-read for  
103 familiarisation with the data and an inductive qualitative framework analysis was  
104 conducted<sup>(18)</sup>. Data organisation was supported by NVivo11 (QSR International).

105 The first stage of the inductive analysis was conducting open coding of a subset of  
106 transcripts; passages of text sentences and paragraphs were individually coded (by  
107 ST and AS) and ascribed attributions (i.e. coding anything seeming relevant from as  
108 many different perspectives as possible). Secondly, ST and AS met to discuss  
109 coding, with differences or anomalies being discussed until consensus was achieved  
110 and no new codes were identified. This led to the development of a definitive coding  
111 framework and the entire dataset was coded accordingly (see Figure 1.).

112 A spreadsheet was generated and the data were 'charted' into the matrix. Charting  
113 involves summarizing data by category from each transcript so that coded data  
114 pertaining to individual interviews can be identified across the data set. Charting  
115 enables characteristics of and differences between the data to be identified, and an  
116 ability to map connections between categories to explore relationships and/or  
117 causality. Thus, framework analysis enabled a deep exploration of the data in a  
118 systematic and organised way and following repeated interrogation, reflection and  
119 synthesis, six themes emerged from the framework analysis. Relationships and  
120 influences between themes could be clearly identified in the data (Figure 2) with all  
121 themes influencing ongoing preferences for a VC service.

122

## 123 **Results**

124 Twelve families took part, which included thirteen parent and five child participants  
125 from eight outreach clinics (Table 1). The final sample included a range of ages and  
126 CKD stages representative of the regional paediatric nephrology population.

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## Theme One: Logistics

Seven families used a personal computer (PC), two used tablets and three used smartphones. Connection problems were raised in all but two interviews and usually lasted a few minutes but in one case, 25 minutes. Browser updates were often required to enable connection, needing telephone support from the dietitian. Once established, parents found the system simple, even when technologically inexperienced:

*'I was panicking, thinking oh, like, I don't do technology, I'm rubbish!.... I don't even know how to switch a computer on! When it was like... download an app...go to this email, I was thinking 'oh no', but actually it went really smoothly.'* (Natalie's mother)

Parents often perceived that their systems were out of date:

*'Well it was difficult to start with, it took me 25 minutes to actually get going, but that is technology for us, which is a bit of a shame. My computer is a bit slow so it's probably my fault anyway.'* (William's mother)

Most families did not report audio-visual issues; minor time-lags occurred in six VC, unrelated to geographical distance. Neither dietitians nor parents felt this affected their experience. Security concerns were negligible; parents felt they had been made aware of the risks of a webcam and microphone in their personal environment. However, it became evident that the dietitian wasn't always aware who else was present in the room at home, raising confidentiality concerns. One mother suggested:

*'You may need to consider conversations that parents might want to have with you, without their children overhearing.'* (Nicholas's mother)

Conversely, feelings of enhanced privacy were reported, compared to:

*'...corridor conversations in clinic.'* (Nicholas's mother)

*'..anyone walking in (referring to other staff entering the clinic room).'* (Thomas's mother)

## Theme Two: Understanding Information

Drawing comparisons to face-to-face, phone and email conversations, parents and children valued being able to see the dietitian, especially if they had not met face-to-face. In screen-share mode diet sheets, growth charts and blood results could be viewed by all. Parents commented that in a face-to-face clinic, there is no time to process information on growth charts but screen-sharing, with discussion, enabled understanding of growth patterns, giving parents some relief and encouragement to continue dietary interventions:

*'It was really useful. I haven't seen my child's growth-chart for a long time. At one time she wasn't gaining any height or weight but (the dietitian) showed me the centiles and she's going up now. So, she is ok and this was nice to see.....we were thinking, "Well we are doing all this and she's not getting anywhere!" but now I can see that she is..' (Ellie's mother)*

Where children attend only at outreach clinics, specialist dietitians advise on email and by telephone. Screen-sharing of diets sheets enabled conversation directly with children rather than through a parent proxy by telephone. Children could generate their own ideas and questions:

*'I think on the phone, I might write it down and take it in, but my son was also able to look at it and say what he liked. We both looked at it at the same time I saw bits, but he was like... "ooh! I like that".... so that led on to other things ... you know it created more leads.' (Thomas's mother).*

Practical aspects were also raised by the same parent:

*'I just think, If I had something I could show you in the fridge, I could get it out and show you. You could tell me if its ok.' (Thomas's mother)*

### **Theme three: Family Engagement**

Engagement with VC was good but influenced by the child's age. Pre-school children were not anticipated to have direct involvement and when one tried, the result was a chaotic VC, disengaging the parent. Dietitian interviews confirmed parents' reports that school-age children engaged positively. Nine year old William, who had not previously engaged, surprised his parents with eye contact and discussion:



188 *'He was really looking forward to doing it. He took the lead in it anyway... he loved it!'*  
189 (William's father)

190 Twelve year old Natalie regularly attended the specialist centre and lived 251  
191 kilometres away. For her, an important benefit was avoiding long journeys to protect  
192 leisure time:

193 *'It was very quick and easy. It didn't take time out of the day. We had pancakes and*  
194 *went to out for lunch. We went to the beach .....we didn't have to wake up at 5am to*  
195 *drive...I could have a lie in.'* (Natalie)

196 Increased motivation to engage was reported:

197 *'You kind of felt he wanted to be there, not just because Mum had told him. He*  
198 *wanted to engage. ....he was a bit more positive, generally rapport was really good'.*  
199 (Dietitian)

200 Several parents explained that anxiety over time and travel meant that they didn't  
201 always stay to see the specialist dietitian in clinic, being keen to leave to collect  
202 siblings or administer treatment such as feeds or dialysis.

203 *'It's just very time consuming. The clinics often run late as well and when your other*  
204 *children are at home being looked after by someone else, you just want to get*  
205 *home.'* (Ellie's mother)

206 An adolescent with communication difficulties was overwhelmingly in favour of the  
207 VC; his parent related this to the closeness of the screen. This family also praised  
208 the efficiency and confidentiality of the VC:

209 *'It was more efficient... because it was all there, all the information had been*  
210 *prepared beforehand. In clinic there is a lot of hanging around, there are*  
211 *conversations in the corridor, and you've got to go off, have bloods...It was*  
212 *timesaving.* (Nicholas's mother)

213

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215 **Theme Four: Establishing Trust**

216 Despite half of the participants having never met the dietitian that delivered their VC,  
217 they described it as:

218 *'Personable and friendly'* (Amelia's mother)

219 *'More personal than a telephone call'* (Sid's mother)

220 Opinions varied as to whether a first-time meeting using VC was appropriate:

221 *'We have known this dietitian since he was born.... I wouldn't have wanted to do it if*  
222 *we had not met the dietitian before.'* (Nicholas's mother)

223 *'Oh god yeah!.... Yeah, definitely!..... I think it feels quite comfortable.'* (Natalie's  
224 mother)

225 And, demonstrating the trust in professional status regardless of prior meetings:

226 *'You are all professionals aren't you ..... I am quite easy going. I don't mind*  
227 *meeting people for the first time over the videoconference.'* (Ellie's mother)

228 Further inductive exploration found that a VC at home gave a sense of familiarity and  
229 intimacy, providing a more comfortable environment for children.

230

## 231 **Theme five: Willingness to change**

232 Willingness to change was identified in several conversations; older children  
233 contributed new mealtime ideas considering their diet restrictions. Parents  
234 acknowledged the benefit of direct conversation between the dietitian and the child,  
235 often with a sense of relief:

236 *'I think at a later date it would be really beneficial to have (the child) involved (in the*  
237 *VC) as well; you know, rather than Mummy just telling her what to eat, someone else*  
238 *could tell her.'* (Amelia's mother)

239 The findings of this theme strengthened the interpretation the themes 'Understanding  
240 Information' and 'Establishing Trust'; an openness to change was perceived after  
241 accessing specialist support, gaining new understanding, and building a rapport  
242 during the VC.

243

**Theme six: Preferences**

Where local dietetic face-to-face services were accessible, parents wanted this to continue. Due to the complexity of advice and service constraints, local services were only in place for three families, all who expressed a desire for a VC to supplement local dietetic care, rather than substitute. Parents valued a direct link to the specialists:

*'When we were in our local hospital, every time we had a concern or a query or anything.... they had to go and phone the renal ward to find out what the answer was..... it would be good to have a direct link, just to get some direct support really.'* (Robbie's mother)

All children reported a desire for future VCs. Younger children enjoyed the novelty of using the computer and older children enjoyed the familiarity of screen-based conversations. Convenience was important to parents as long as an appointment was pre-arranged. Most suggested email, or to a lesser degree, telephone, would complement the service well:

*'Email is easy as I can sit and do that later when the kids have gone to bed and I have peace and quiet. The videoconsultation is nice because you can see a proper person.....Timing is the key; it is a really good way of doing it but for us we would need to have a set appointment.'* (Robbie's mother)

*'I would be happy with video and emails, it's easy, y'know'.* (Oscar's mother)

Parents of children with severe CKD, who attend the specialist centre regularly still requested VC to reduce time spent there. They valued the likelihood of improved engagement and protected virtual time with the dietitian:

*'You know the time is your time- people aren't coming in and taking you away for other things.'* (Thomas's mother)

## Discussion

This study demonstrates that using VC to support regional paediatric specialist dietetic care is feasible, acceptable and beneficial to those living with CKD. Convenience, efficiency and specialist dietetic access positively influenced engagement. Parents and older children described enhanced understanding when viewing on-screen information during the consultation. This led to a perceived enthusiasm for dietary change and preferences for ongoing VC as part of their dietetic care plan.

To our knowledge this is the first qualitative study of VC using home technology in the UK paediatric population. Familiar public VC platforms such as Skype have been internationally researched in healthcare<sup>(19, 20)</sup>, but security concerns exist<sup>(21, 22)</sup> and in the study location, its use was not permitted.

The lack of security and privacy concerns in this study may have been influenced by high trust levels in regular service users informed of potential risks. Similarly, concerns to privacy are not frequently voiced in other studies of VC within a patient's home<sup>(23-25)</sup>, however, relevant studies are set in neonatal situations where parent vulnerability may influence perspectives. Population differences mean these studies are not wholly comparable, but the current study also confirms that VC is not considered intrusive for this caseload. A minor concern was the possibility of sensitive information being overheard by children. Use of headphones could be recommended but is not a full solution; risks should be considered and consent to VC documented.

Where prior concerns over technological competence existed, parents experienced that VC software was straightforward to use. Doubts of capacity for technology may limit VC uptake<sup>(26)</sup>, but this is influenced by age and the current study supports research that younger adults find VC 'extremely easy' and superior to telephone support<sup>(27, 28)</sup>. Regular use can limit connection difficulties and improve user confidence<sup>(28)</sup> but consideration is required where only a few contacts are required annually. VC at home is less prevalent than facilitated clinic use and more evidence is needed to ensure families can use it without hands-on professional support<sup>(20, 29)</sup>.

It is likely that recent improvements in technology resulted in less abundant audio-visual difficulties than reported in the literature<sup>(24, 28)</sup>. Occasional dark images were rectified by guidance to sit in a well-lit area. 'Time-lag' was common in this study and others<sup>(20, 24)</sup> but users develop a 'pausing' style to overcome this<sup>(30)</sup>.

Screen-sharing contributed to improved understanding; of growth charts in particular. Growth retardation remains a major problem in CKD, with short-stature posing psychological and medical challenges<sup>(31)</sup>. Anecdotally, electronic growth charts appear difficult for a patient to view in clinic as the screen is in front of the professional, not the patient. In this study parents reported viewing information more clearly on their own devices, even on a small screen.

Good therapeutic trust and rapport is associated with improved adherence<sup>(32)</sup>, so virtual rapport must be understood. In this study, opinions were divided regarding the need for established face-to-face relationships before moving to VC. Age and technological confidence may additionally influence rapport; although positive virtual therapy alliances are described by adolescents, some parents prefer face-to-face consultations<sup>(33)</sup> and find a prior physical meeting preferable<sup>(33-35)</sup>.

The findings strongly support VC as a tool for improved engagement, particularly with older children and this is significant regarding self-care and transition. Developing evidence suggests that digital communication enables young people to take greater responsibility for their health and improves health professionals' access to young people<sup>(36, 37)</sup>. Talking to children through their parents can make children feel 'invisible'<sup>(33)</sup>. Gaining knowledge independently provides opportunities for self-care<sup>(38, 39)</sup>.

Risks of reduced engagement are acknowledged in this study. Interruptions in the home may be distracting<sup>(40)</sup>, but paediatric specialists are somewhat used to lively consultations, and visual images may offer more chance to anticipate an interruption compared to telephone. Statements show VC at home provided familiarity for children; studies agree the experience is 'as if sharing the same room'<sup>(41)</sup>. In line with other studies, parents described children as 'in their comfort-zone'<sup>(34)</sup>. These findings support research suggesting better therapeutic relationships are developed using VC compared to telephone<sup>(27, 42, 43)</sup>.

Regarding willingness for dietary change, parents believed the VC influenced new ideas and promoted enthusiasm for change. It is unknown if this will result in actual behaviour change in children, but evidence exists for adults<sup>(14)</sup>. Active engagement motivates adolescents to meet treatment goals<sup>(44)</sup> so success seems possible. This study also added evidence to the perception that VC's are enjoyable for children<sup>(34)</sup> and thus potentially 'motivating'<sup>(23)</sup>. Virtual access to the child's home environment can contextualise advice<sup>(34, 40)</sup>, making interventions more manageable.

Preferences for ongoing VC were influenced by its efficiency. Studies show that VC is associated with decreases in travel time and less disruption to education and employment <sup>(23, 35, 45)</sup>. The current study revealed parents appreciated a prepared and organised VC clinic in comparison to attending a multi-professional clinic at the specialist centre. These busy hospital clinics involve planning the movement of children around numerous multidisciplinary staff, with often frustrating waits for families. With VC, families seemed prepared and relaxed in their environment. This was reported by several parents in this study and is in line with other research<sup>(34, 46)</sup>.

Preferences were also influenced by access to specialist knowledge. Despite some having a trusted local dietitian, all families wanted a complimentary specialist VC. The paediatric CKD population is relatively small with significant variability in dietary needs. Dietitians working in general hospitals have little opportunity to develop renal expertise and are indeed not expected to. This supports UK recommendations that children in CKD stages 3-5D should have a specialist renal dietetic review at least annually<sup>(6)</sup>. Early dietetic advice supports prevention of bone mineral disorders<sup>(47)</sup> and optimises growth<sup>(48)</sup>. Although specialists provide training and lead care<sup>(6)</sup>, local teams rarely have capacity to prioritise these children<sup>(11)</sup>. If adequately resourced, VC could undoubtedly improve dietetic care, especially if supplementary to face-to-face care<sup>(34, 35, 41, 49)</sup>. More research is needed to determine if VC could be a sole communication method in earlier disease and if this jeopardises face-to-face services<sup>(24, 26, 34, 45, 50)</sup>. Quantitative research should investigate if VC developments can result in improved engagement with dietetic services and improved nutritional outcomes. This should not be restricted to children with renal disease and encompass all children with dietary related disease to enable a much larger sample.

## Rigour and reflexivity

The researcher is a dietitian (ST), experienced in regional service challenges, so reflexive practices were used to ensure prior beliefs, values and predictions did not shape data interpretation. A second researcher (AS), who is not a dietitian nor has experiences with the nephrology service, assisted with developing the coding framework and analysis, adding further validity<sup>(15, 51)</sup>.

## Limitations:

Due to timeframes, the study design included just one VC experience which may negatively bias perspectives, as technical difficulties are less likely to exist with established frequent use<sup>(28)</sup>. A second limitation was that a few families had established trust and rapport before the study as a consequence of usual care.

## Conclusion:

This study presents promising evidence that videoconsultation can improve engagement with children and parents who may otherwise present barriers such as distance, time limitations, and motivation. Enhanced engagement, during an isolated VC, was demonstrated by adolescents in the study, but further research is required to determine if engagement with dietetic services will improve overall. The chosen VC system was secure and technologically feasible but families required telephone support during initial set-up. Screen-sharing of information generated practical discussion and was regarded superior to telephone calls. Children preferred VC, whilst parents felt VC was an efficient, trustworthy supplement to current dietetic care. VC complements NHS plans to improve quality and equity across networks<sup>(5)</sup>. Further research and evaluations are required to explore if dietary adherence and thus nutritional outcomes in paediatric CKD can be improved using a VC service.

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Theme	Codes	Definition	When to use	Example text
Willingness to change	Embracing new perspectives/idea's	New understanding supporting dietary/behavioural change	When statements imply new knowledge or understanding gained will lead to positive dietary actions	'A picnic...that's some before. To be hones w .....its nice to try again we don't want him on
	Agreeable to dietary change/ maintenance			
Logistics	Operating difficulties	Any technological issue disrupting the VC or preventing it from starting. Any problem with attending appointments	When perspectives on connection difficulties, sound, visual quality are raised. Operating difficulties. Concerns regarding security/privacy.	'I was panicking, think technology, I'm rubbish switch a computer on smoothly' 'It took 25 that's technology for slow.' 'You may need that parents might w their children overhea
	Technical issues with VC			
	Privacy/ security of VC			
Family Engagement	Engagement of participants and others	Describes family support and willingness to use VC to consult with dietitians and benefits or difficulties with this	When family members or children comment about ability to engage due to convenience/ease of access/time commitment/timing of appointment and the benefit/disadvantage of this to family life	'It's the school holiday centre) literally takes got to have an appoint we've been to a soft p we have been to the t that (the child) was at consultation, ... he act computer..... He stayed whole consultation, m and was answering at
	Attendance to VC fits around family life			
	Barriers to engagement			
	Facilitators of engagement			

Figure 1. Excerpt from the coding frame

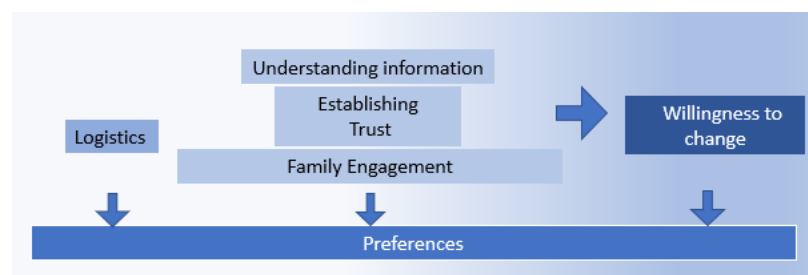


Figure 2. Themes and their relationships